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Privacy in the Commercial World: Online Consumer Privacy Concerns: Hearing Before the H. Subcomm. on Commerce, Trade, and Consumer Protection of the H. Comm. on Energy, 107th Cong., Mar. 1, 2001 (Statement of Chai R. Feldblum, Prof. of Law, Geo. U. L. Center)

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PRIVACY IN THE COMMERCIAL WORLD

HEARING

BEFORE THE

SUBCOMMITTEE ON
COMMERCE, TRADE AND CONSUMER PROTECTION

OF THE

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6. Free Expression and Privacy Protection are Complimentary Values

On the question of the privacy and freedom of expression, this is clearly not a zero-sum relationship. This can be shown by the fact that there are many countries today with little regard for personal privacy or freedom of expression. The success of the US legal system is to preserve both interests, to safeguard free expression and to protect individual privacy.

There are also a series of cases that make clear that privacy and the First Amendment are complimentary interests. In MacIntyre v. Ohio, for example, the Supreme Court struck down an ordinance that required the publisher of a handbill to place her actual name on the pamphlet. In so doing, the Court recognized that the freedom to express ones views includes also the right to withheld ones identity. There are many other examples in American law where we safeguard privacy to promote free expression and freedom of association. It's worth noting, for example, that the freedom to vote as one wishes in a democratic society is safeguarded by the privacy of the voting booth.

There are tough cases where the First Amendment and privacy interests collide. The Supreme Court, for example, must determine this term whether the press may publish the contents of a private telephone call obtained by means of an unlawful wiretap. EPIC, my own organization, dedicated to both the protection of privacy and the promotion of free speech, struggled with the question on which side we would file an amicus. In the end, we decided it was too difficult a case. But recognizing that there are, in some instances, difficult case does not mean as a general matter that it is not possible to protect privacy and to promote free expression.

7. Federal Privacy Legislation Typically Does Not Preempt State Law

The issue of federal preemption is arising increasingly in discussions about privacy protection. It is important to understand that as a general matter, federal privacy law operates as a baseline and does not preempt stronger state statutes. This is clear from laws such the Video Privacy Protection Act of 1988 and the subscriber privacy provision in the Cable Act of 1984. This approach was reaffirmed recently in the privacy provisions of the Financial Modernization Act of 2000 and the HIPAA regulations.

There are important reasons in our form of government to continue to allow the states to operate as "laboratories of democracy." Congress may fail to act or it may act in such a way that reduces or limits the protections that a state might otherwise choose to provide for its citizens. States may also innovate and explore different approaches to common problems. California, for example, has recently passed legislation to address emerging privacy concerns and Maryland is now looking at new legislation that would provide important new protections.

8. Public Support for Privacy Protection is a Significant Consideration in the Legislative Process

In understanding the protection of privacy in America it is critical to keep in mind the central role that the Congress and the state legislatures have played in safeguarding privacy. In some instances, it has been the courts that have established rights of privacy, but more often it has been the legislature that has set out by means of statute the rights and responsibilities associated with the use of personal information in the commercial realm.

My belief is that there is today widespread public support to establish Fair Information Practices for the collection and use of personal information in the commercial sector. There is a strong American tradition to protect privacy in law, many legislative precedents and broad based public support. The question is whether Congress will accept the challenge and act to safeguard this right, described by Justice Brandeis "as the most comprehensive of all rights and the one most cherished by a free people."

I appreciate the opportunity to appear before the Committee today and will be pleased to answer your questions.

Mr. STEARNS. Professor Feldblum?

STATEMENT OF CHAI R. FELDBLUM

Ms. FELDBLUM. Thank you, Mr. Chairman, and members of the subcommittee.

My name is Chai Feldblum. I am a law professor at Georgetown University Law Center and director of the Federal Legislation Clinic, where we have worked on the issue of medical privacy for a

number of years for various organizations. But I am testifying here today in my personal capacity as a law professor—although I am used to answering questions and being grilled by students. I don't know; I guess the new generation of students is quite different—to talk about my experiences in employment discrimination and medical privacy. And instead of talking about the minute details of those areas, of which there are many, instead of getting bogged down in that to sort of step back and talk about conceptually why it makes sense for government to regulate in these areas.

Now, my written testimony gives you a description of the privacy requirements of the ADA, and I am not going to repeat those here. Basically, employers cannot ask questions of employees about their medical conditions at certain stages of the application process. They can collect a whole range of medical information before actually hiring somebody. That medical information has to be kept confidential, and employees with medical conditions are forced to disclose those conditions to their employers if they want reasonable accommodations.

So what I want to focus on is why is government regulation of privacy in this way appropriate? I think that when government regulates conduct that it is otherwise permitted to regulate, such as employment discrimination, it can also regulate speech that would lead directly to such discrimination. So, for example, government can say you can't refuse to hire someone because she is pregnant. You also can't refuse to ask someone if she is going to become pregnant.

Similarly, you can't ask applicants about their medical conditions if that means they won't get a fair chance to be considered for a job, but you can certainly find out about their medical information if that means they are not going to be qualified. None of us want to have 911 operators unable to hear. I mean, that is not the point.

Now, in the area of medical privacy, the context that we are dealing with is that patients believe that they have a confidential relationship with their medical professional, and yet, that expectation is compromised every day by the interconnected research, medical, treatment, payment, quality system that we live in. The California Health Care Foundation has done a fascinating presentation of where our medical information actually goes, and I would absolutely recommend that presentation to everybody.

Now, of course, a certain amount of individually identifiable health care information has to flow through our medical system. As someone who has represented disability organizations, I can tell you that people with disabilities have a very pragmatic view of this issue. Bottom line: they want a health care system that is effective and efficient. But precisely because the interaction in the medical system starts with a contractual relationship between the patient and the provider, the individual must feel assured of certain ground rules that their information will, in fact, be used appropriately.

Now, let me end by saying that Congress, in 1996, did tell the Department of Health and Human Services to implement nine standards, and these were standards about transaction codes and identifiers and data security, et cetera. I think it made sense for Congress to interact in this way with the private parties because

the only way to have consistent, uniform standards in the health care system is if, in fact, government intervenes and says everyone has to abide by these standards. That is what eight of those standards were about.

But at the same time, government has to make sure that privacy protections are built in as well. That is the ninth standard.

Well, I very much appreciate that you are looking at this issue, and I look forward to answering any of your questions.

Mr. STEARNS. You roughly have 2 minutes left.

Ms. FELDBLUM. Oh, I do. My thing over here says stop.

Mr. STEARNS. I just checked.

Ms. FELDBLUM. Well, then, I am going to give you my last two paragraphs.

Mr. STEARNS. There you go.

Ms. FELDBLUM. And I know that if you had gone home without them, it just would not have been the same.

I know that there is controversy about the regulations that have been put out, but for purposes of this big picture hearing, I want to stress the need to analyze privacy within the specific context of which the perceived need to regulate arises, and if there is anything that you get from this hearing and to me anything about doing—thank you; I know you agree, a big picture hearing as opposed to a hearing on a particular bill, it is to focus on the context in which that privacy concern arises.

In the health care arena, that context is a longstanding belief between patient and doctor that medical information should be kept confidential juxtaposed with the reality of a complex health care treatment, payment, research, quality and marketing system that uses a significant amount of individually identifiable information without patients' explicit consent although with some patients' dimly sensed fear.

The role of government, I believe, is to bring clarity and confidence to this area. Thus, the goal of any system of privacy regulation should be to enhance the treatment, payment, research and quality aspects of our health care system through creating a workable privacy system that gives patients trust and ensure that health care entities can engage in the marketing necessary to their financial health consistent with consumer consent.

Now, I can assure you as someone who has worked in this area for 6 years that there is a lot of debate and a lot of detail within that sentence. What is a workable system? But I think there is a common principle that there is a role for government to ensure that there are uniform, consistent standards and confidence and trust in the system. That is what you should do in the medical privacy area, and consistent with the context of these other areas, that is what you should do in other areas as well.

Thank you.

[The prepared statement of Chai R. Feldblum follows:]

PREPARED STATEMENT OF CHAI R. FELDBLUM, PROFESSOR OF LAW, GEORGETOWN UNIVERSITY LAW CENTER

Mr. Chairman and Members of the House Subcommittee on Commerce, Trade, and Consumer Protection:

Thank you for inviting me to testify today regarding "Privacy in the Commercial World." My name is Chai Feldblum. I am a Professor of Law at Georgetown Univer-

sity Law Center, and Director of the Law Center's Federal Legislation Clinic. I created the Clinic in 1993 with the goal of training law students to be "legislative lawyers": that is, lawyers who are equally at ease with law and with politics. My goal is to train lawyers who are steeped in law and who like reading legal text, *and* at the same time, who are sophisticated about politics, know how to speak and write in "English" rather than in "law," and who like the particular world of political negotiation. The goal is to produce lawyers who will actually be *helpful* to you and your staff as you create legislation to address the needs of our country.[1]

I also wear the traditional hat of an academic professor. My academic legal writings have been primarily in the area of civil rights, with a focus on disability law and sexual orientation and the law.

I appear before you today as an amalgam of those roles. In my life before teaching, I was the principal lawyer representing the disability community in the drafting and negotiating of the Americans with Disabilities Act—including those provisions impacting on privacy and confidentiality. As Director of the Federal Legislation Clinic, I have represented the National Association of People with AIDS (NAPWA), in its capacity as co-chair of the Privacy Working Group of the Consortium of Citizens with Disabilities.[2] For six years, we have worked on behalf of the disability community toward passage of comprehensive federal medical privacy legislation. More recently, the Clinic has represented the Family Violence Prevention Fund, which is also concerned with enhancing medical privacy in this country.[3]

Today, however, I wish to draw on those experiences to share with you some general observations about protecting the privacy of our nation's citizens.[4] I am less familiar with the academic and advocacy debate regarding proposals to regulate consumer information databanks developed by businesses (the subject of some of the writing of my co-panelists), and more familiar with the debate regarding privacy as it relates to employment discrimination and medical information. What I hope to do, therefore, is share with you some observations on the latter forms of privacy, and perhaps extrapolate from that some observations on privacy in general.[5]

A useful place to start is a sentence from my co-panelist Eugene Volokh's May 2000 article on freedom of speech and information privacy: "'[P]rivacy' is a word with many meanings, and with such words both judges and laypeople often shift from one meaning to the other even in cases where the meanings have little in common."[6] I completely agree with that observation. While I do not necessarily agree with my co-panelist's subsequent conclusion that harmful analogies are more likely be drawn if the privacy of consumer information databases are regulated,[7] I believe

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[1] For an explication of "legislative lawyering," see "Five Circles of an Effective Coalition" and "What is Legislative Lawyering?" *available at* http://www.law.georgetown.edu/clinics/flc.

[2] The Consortium for Citizens with Disabilities (CCD) is a Washington-based coalition of approximately 100 national disability, consumer, advocacy, provider and professional organizations that advocate on behalf of 54 million children and adults with disabilities and their families. As advocates for persons with disabilities, CCD supports strong privacy protections that give health consumers confidence that their information will be used appropriately and that permit the continued viability of medical research and delivery of quality health care.

[3] The Family Violence Prevention Fund is a leading national organization that advocates on behalf of the millions of women and children who are the victims of domestic violence each year. The Fund runs several major programs that deal specifically with health care and domestic violence. As advocates for people affected by domestic violence, the Fund supports privacy protections that will give victims confidence that their personal information will be used appropriately.

[4] Thus, I appear before you today in my personal capacity.

[5] My observations with regard to employment discrimination and medical privacy should not be taken to mean that I do not believe there are also serious policy considerations for applying privacy regulation to consumer databases of non-medical information. Indeed, while I consider the work of my colleague, Eugene Volokh, see below, to be of superb quality, I believe Congress must be cautious in chilling in its own action in anticipation of some speculative long-term constitutional concern. While I have touted the advantages of Congress drafting a narrowly circumscribed bill to address a real, documented public policy evil to be remedied, so as to avoid creating an inviting target for the Supreme Court to further narrow Congressional power, see testimony of Chai R. Feldblum before the Senate Judiciary Committee on the Religious Liberty Protection Act, September 9, 1999, I have never believed that Congress should fail to act when there is a clearly defined public policy problem and the recommended legislative response is not clearly unconstitutional. Of course, as Congress acts, it is useful to have the background analysis of scholars such as my co-panelists who may entertain some doubts about such actions.

[6] Eugene Volokh, *Freedom of Speech and Information Privacy: The Troubling Implications of a Right to Stop People from Speaking About You,* 52 Stan. L. Rev. 1049, 1102 (2000) (hereinafter *Freedom of Speech*).

[7] Volokh argues that "once restrictions on people's speech are accepted in the name of 'privacy,' people will likely use them to argue for other restrictions on 'privacy' grounds, even when the matter involves a very different sort of 'privacy.'" *Id.* at 1102. By contrast, my colleague at Georgetown University Law Center, Julie Cohen, has written some interesting pieces presenting a different point of view. *See* Julie E. Cohen, *Examined Lives: Informational Privacy and the*

he has helped enhance the practical debate about privacy by illuminating its various meanings and components.[8] What I would like to do is focus on two areas where the concerns are somewhat different, I believe, than those that arise in the context of consumer information databases. The best way for Members of Congress to carry out the hard work of figuring out what legislation to pass (and how to craft such legislation) depends, I believe, on developing a sensitive understanding of the context in which various privacy concerns arise.

The two areas on which I would like to focus are employment discrimination and medical privacy. Again, I do not plan to focus on the minute details of these areas (and there are a number of very minute details in each of these areas, I assure you), but rather, on the broad conceptual reasons for the enactment of legislation in these areas. Indeed, in both employment discrimination and medical privacy, Congress has already acted to some extent—and there are lessons to be drawn from those enactments.

During passage of the Americans with Disabilities Act (ADA), Congress chose to draw on Section 504 of the Rehabilitation Act of 1973, a law that prohibits programs that receive federal funds from discriminating on the basis of disability. That law, and the regulations issued pursuant to the law, provided Congress with a 17-year track record of substantive non-discrimination principles on the basis of disability. Section 504 was not focused on privacy, and yet the law included some important privacy components that were carried over to the ADA.

Congress recognized that people with hidden disabilities (such as breast cancer or HIV infection or diabetes) often do not get the chance to be fairly considered for a job because the employer finds out—through questioning at an interview or through a medical examination or questionnaire—that the applicant has a particular medical condition. In such cases, the employer may choose not to hire the person because of unsubstantiated fears regarding the person's possible absentee rate or the response of co-workers, or because of possibly substantiated fears of higher health care costs that might be associated with that individual. In either case, in such circumstances the individual is judged not on the *merits* of his or her ability to *do* the job, but rather on ramifications that (justly or unjustly) flow from the individual's medical condition.

In some cases, of course, an individual's medical condition will impact directly on the person's ability to perform the job. For example, we all want our airline pilots to be able to see, our truck drivers to be able to drive, and out "911 operators" to be able to hear.

The ADA thus creates privacy rules that ensure applicants are provided a *fair* chance to be *considered* for a job, but also ensures that employers are permitted to hire only *qualified* employees. Under this framework, employers may not ask job applicants to disclose their medical conditions during the initial stages of an application process. Rather, after a conditional job offer is extended, employers may ask applicants to respond to questions about their medical conditions (or to take a physical examination)—and based on that information, employers may refuse to hire employees who are not qualified for the relevant jobs.[9]

Subject as Object, 52 Stan. L. Rev. 1373 (2000); Julie E. Cohen, Privacy, Ideology, and Technology: A Response to Jeffrey Rosen, 89 GEO. L. J. xx (2001)(forthcoming). *See also* Janlori Goldman, *Privacy & Individual Empowerment in the Interactive Age*, VISIONS OF PRIVACY: POLICY CHOICES FOR THE DIGITAL AGE (C. Bennett & R. Grant eds. 1999).

[8] The work of my other co-panelists has also been of significant use in this regard. *See, e.g.*, Solveig Singleton, *Privacy Versus the First Amendment: A Skeptical Approach*, 11 Fordham Intell. Prop. Media & Ent. L. J. 97 (2000) (hereinafter *Privacy*); Fred H. Cate, *The Changing Face of Privacy Protection in the European Union and the United States*, 33 Ind. L. Rev. 173 (1999); Wayne Madsen, David L. Sobel, Marc Rotenberg, David Banisar of The Electronic Privacy Information Center, *Cryptography and Liberty: An International Survey Of Encryption Policy*, 16 J. Marshall J. Computer & Info. L. 475 (1998).

[9] 42 U.S.C. § 12112(a)-(c). The ADA had originally incorporated a stricter rule which permitted employers to request from applicants only that medical information which was directly related to the job. After negotiations with the business community and the Bush Administration, however, that provision was modified to allow employers to request any medical information. Chai Feldblum, *Medical Examinations and Inquiries Under the Americans with Disabilities Act: A View from the Inside*, 64 TEMPLE LAW REVIEW 521, 535-537 (1991) (hereinafter *Medical Examinations*). The key protection for people with disabilities, however, is that the medical information must demonstrate they are not qualified for the job. Whether a person is qualified for a job will depend on whether there are reasonable accommodations that will enable the person to perform the job functions. 42 U.S.C. § 12112(b)(5)(a); *see generally*, Chai Feldblum, *Anti-discrimination Requirements of the ADA*, IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT: RIGHTS AND RESPONSIBILITIES OF ALL AMERICANS (L. Gostin & H. Beyer eds. 1992).

Once employers have collected medical information about applicants through such questioning or examinations, that information must be kept confidential.[10] In addition, if an employer seeks medical information from an employee on the job,[11] that information similarly must be kept confidential. What that means is the following. If medical information indicates that an applicant is not qualified to perform a job, or that an employee is no longer qualified to perform the job, the medical information may be used to refuse to hire or to fire that applicant or employee. This includes, obviously, disclosing the medical information to the relevant person with employment authority. However, if the medical information does not indicate that an applicant or employee is unqualified for a job, then that information cannot be circulated within the employment setting.[12]

There is a flip side to the confidentiality requirements of the ADA. Many people with medical conditions wish to keep their conditions private, and do not wish either their employer or their co-workers to know of their conditions. Often, this does not pose a problem. However, in certain circumstances, an employee is *required* by law to *divulge* his or her condition, even if such disclosure is personally difficult for the individual. These circumstances arise when an employee seeks a modification of an employment practice or procedure (a "reasonable accommodation") because of his or her medical condition. Thus, for example, if an employee has a health condition that requires her to receive a two-hour treatment once a week, and she seeks time off to receive that treatment—she *must* disclose the existence and nature of her health condition in order to receive the benefit of the reasonable accommodation requirement under the ADA.[13]

What can we extrapolate from these employment requirements? As I noted, it is important to view privacy issues in the *context* in which they arise. When government regulates conduct that it is otherwise permitted to regulate (for example, prohibiting discrimination in employment contracts based on race, sex, or disability), I believe it is also permitted to regulate speech that would directly *contribute* to such discrimination. Thus, the government may not only prohibit an employer from discriminating on the basis of pregnancy, but may also prohibit an employer from asking a prospective job applicant if she is planning to become pregnant.[14] Similarly, employers may be restricted in the questions they ask of applicants regarding their medical conditions during the application process.[15] These restrictions should be narrowly tailored, however, to the harm sought to be prevented by the government. For example, such tailoring is evident in the structure of the ADA, which permits employers to seek medical information prior to actually hiring an individual.

The context of the employment relationship also justifies the fact that government *compels* certain speech on the part of some employees with disabilities. As a general matter, of course, government may not compel speech on the part of its citizens.[16] But if an individual enters a contractual relationship with an employer, in which certain facets of that relationship are regulated by the government, then that individual can be expected to conform to expectations in the relationship that have been established through the government regulation. Thus, for example, although an individual must forgo some privacy rights if she wishes to take advantage of the rea-

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[10] 42 U.S.C. § 12112(c)(3)(B).

[11] After an employee is on-the-job, medical inquiries may only be made if they are job-related. 42 U.S.C. § 12112(c)(4)(A); Feldblum, *Medical Examinations*, at 538-540.

[12] The only individuals who may gain access to these records are: supervisors who may be informed regarding necessary restrictions or reasonable accommodations; first aid and safety personnel, when appropriate, and government officials investigating compliance. 42 U.S.C. § 12112(c)(3)(B). According to regulations issued by the Equal Employment Opportunity Commission, employers may also provide such information to worker's compensation offices upon the filing of a claim by an employee. See EEOC Interpretive Guidance to 29 C.F R. § 1630.14(b).

[13] EEOC Interpretive Guidance to 29 C.F.R. § 1630.9.

[14] See EEOC Sex Discrimination Guidelines, 29 C.F.R. § 1604.7 (1983); *King v. TWA*, 738 F.2d 255 (8th Cir. 1984).

[15] I do not believe there is much disagreement that speech which effectively constitutes an *act* of discrimination is within government's legitimate power. For example, government may not only prohibit employment discrimination based on race, but may also prohibit an employer from running an ad that seeks "whites only" for a job. The more complicated question is whether, consistent with the First Amendment, government may also prohibit employers from engaging in speech that might lead directly to such discrimination. As noted, I believe government may legitimately do so. In some cases, however, the context in which this speech arises may well be determinative. For example, in *U.D. Registry, Inc. v. California*, 40 Cal.Rptr. 2d 228 (Ct. App. 1995), a state court held that the government could not prohibit only credit reporting agencies from disclosing information regarding certain housing actions, which were otherwise a matter of public record. While I have some questions regarding the outcome of this case, the fact that the relevant information already existed in the public domain was critical to the court's decision.

[16] *See Wooley v. Maynard*, 430 U.S. 705 (1977); *West Virginia State Board of Education v. Barnette*, 319 U.S. 624 (1943).

sonable accommodation requirement of the ADA, that trade seems both appropriate and within the government's power.

A contractual relationship also exists in the area of medical privacy more generally. That relationship has led some commentators, who are otherwise leery of governmental regulation of privacy, to view medical privacy in a different light. Let me take two of my co-panelists as an example. Eugene Volokh has observed that "one sort of limited information privacy law—contract law applied to promises not to reveal information—is eminently defensible under free speech doctrine."[17] Volokh notes that this protection should also cover implied contracts and explains the relevance of this for the medical context:

> This explains much of why it's proper for the government to impose confidentiality requirements on lawyers, doctors, psychotherapists, and others: When these professionals say "I'll be your advisor," they are implicitly promising that they'll be confidential advisors, as least so long as they do not explicitly disclaim any such implicit promise.[18]

A similar observation is made by Singleton in her critique of analyzing privacy primarily as a "right to 'control' information about oneself."[19] As Singleton observes:

> This idea is familiar in medical and legal ethics and perhaps in other special professional relationships. In these relationships the expectations makes sense. The legal and medical professions understand that clients and patients will not confide in them without the right of confidentiality. Even if this right did not exist by statute, it is implicit in the agreements under which a doctor treats his patients or the lawyer counsels his clients. This understanding is informed by decades or even centuries of custom.[20]

The reality, of course, is that the confidential relationship patients believe they have with their medical professionals is compromised every day by the reality of the interconnected medical, research, payment, and marketing system that we live in. The California HealthCare Foundation has developed a fascinating presentation that graphically displays the flow of our medical information in our existing interconnected systems.[21] Thus, for example, during and following one visit to a hospital, a patient's individually-identifiable health information may be sent to a lab, a pharmacy, a pharmacy wholesaler, a drug company, a marketer, an imaging center, a primary care group administrator, a third party administrator, an insurance company, a research institution, a public health department, a medical information bureau, a life insurer, a state insurance board, an oversight or accreditation board, and an employer.

Of course, a certain amount of individually-identifiable health information must flow freely in our health care system in order for the system to work efficiently, effectively, and at a high level of quality. As someone who has represented disability organizations over the years, I can assure you that people with disabilities have a very pragmatic view of this issue. People with medical conditions tend to interact a significant amount with the medical system. Hence, they want an effective, efficient, and high quality health care system, together with the best that increased research and disease management can offer.

But disability rights advocates do not experience their desire for medical privacy to be in conflict with their desire for an effective health care system, and thus they do not view these interests as needing to be "balanced" against each other. Rather, precisely because the interaction with the medical system is, at first onset, a contractual relationship—the interaction works best if patients feels assured of certain *ground-rules:* that their individual medical information will not be disclosed to entities that may use that information to harm them; that their information will be used, within the health care system, in an "appropriate manner;"[22] that they will

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[17] Volokh, *Freedom of Speech,* at 1057.

[18] *Id.* at 1058.

[19] Singleton, *Privacy,* at 122.

[20] *Id.* at 122-123.

[21] I watched this presentation at a conference sponsored by the California HealthCare Foundation in December 2000. It is one I would whole-heartedly recommend to Members of Congress and their staff. A useful summary graphic of "sample data flow" was developed by the Georgetown University Health Privacy project, based on the presentation of the California HealthCare Foundation, and is attached to this testimony.

[22] I put "appropriate" in quotation marks because the debate over health care privacy regulation sometimes concerns the scope of the activities over which patients should be able to control transfer of their individually identifiable information. There are many activities that patients may not realize, at first blush, are "appropriate" uses of their medical information, and yet, such activities may be quite essential for the workings of the health care system. For this reason, the debate often focuses on what providers and plans may legitimately demand—as a pre-condi-

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be provided information about what those "appropriate" uses will be, and that they will have the opportunity to review their own medical records. Thus, establishing an effective system of privacy regulation can enhance the operation of the health care system by increasing individuals= trust and confidence in the initial medical contractual relationship.[23]

As in the area of employment discrimination, Congress has already acted to some extent in the area of medical privacy—although there is work that still needs to be done. In 1996, Congress directed the Department of Health and Human Services (HHS) to develop nine administrative simplification standards for use in the health care system. These standards were to address: "transaction codes and medical data code sets; consistent identifiers for patients, providers, health plans, and employers; claims attachments that support a request for payment; data security; enforcement" and "information privacy."[24] As the General Accounting Office described this Congressional mandate: "Taken together, the nine standards are intended to streamline the flow of information integral to the operation of the health care system while protecting confidential health information from inappropriate access, disclosure, and use."[25]

Congress' action to date in this area reflects, I believe, an appropriate interaction between government and private contractual parties in the health care system. Given the interconnectedness of our health care system, and the increasing use of computer technology, all parties benefit if there are consistent and uniform standards that will be used by all parties to health care transactions. To create such uniformity and consistency—and hence, administrative simplification—government must intervene through the establishment of standards to which all parties must conform. However, as government *facilitates* the uniform entry of our medical information into this administratively simplified system, it must *simultaneously* ensure that privacy standards, policies, and protections are built into the system as well.

Congress took that initial step in 1996, and the Department of Health and Human Services fulfilled its obligation in 2000. While I, as others, are disconcerted that the process will be reviewed yet again,[26] I have no doubt that, as Secretary of HHS Tommy G. Thompson has stated, after reviewing public comments, he intends to "put strong and effective health privacy protections into effect as quickly as possible."[27] I believe the Secretary, as well as the heath care industry, clearly recognize that effective privacy protection facilitates and enhances the doctor-patient relationship.

The reality, of course, is that Congress has not yet acted to ensure that medical privacy protection will exist—as a reality—in *all* contexts in which problems of disclosure may arise. For example, the mandate Congress handed to HHS covered only a select group of entities in the health care system (health care providers, health plans, and health care clearinghouses), and did not cover a range of other entities (such as employers, educational institutions, and financial institutions) that also obtain medical information. While the regulation issued by HHS makes some effort to address subsequent disclosures by such entities, I believe most observers consider there is room for improvement in this area.

The actions that Congress has previously taken in the area of medical privacy, together with the work that remains to be accomplished, provides us with some general observations on the role of government in this arena. As I stated at the outset,

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tion for treating a patient or paying for such treatment—as they enter the contractual relationship with the patient.

[23] A national survey released in January 1999 found that one in six Americans engages in some form of "privacy protective behavior" because he or she is afraid of confidentiality breaches regarding sensitive medical information. These activities include withholding information from health care providers, providing inaccurate information, doctor-hopping to avoid a consolidated medical record, paying out of pocket for care that is covered by insurance, and avoiding care altogether. California Healthcare Foundation, *National Survey: Confidentiality of Medical Records* (January 1999). The survey was conducted by Princeton Survey Research Associates. Results are available at http://www.chcf.org/conference/survey.crfm.

[24] Ms. Leslie G. Aronovitz, Director, Health Care-Program Administration and Integrity Issues, U.S. General Accounting Office, Testimony before the Senate Committee on Health, Education, Labor, and Pensions, February 8, 2001, at 2. The mandate on HHS to implement an information privacy standard was triggered only if Congress failed to enact comprehensive medical privacy legislation by August 21, 1999. Of the nine standards required to be issued, HHS has issued a regulation governing electronic transactions (on August 17, 2000) and a regulation governing information privacy (on December 28, 2000).

[25] *Id.*

[26] See Robert Pear, *"Health Secretary Delays Medical Records Protections,"* NY Times, February 27, 2001, at A14 (reporting that HHS Secretary Tommy G. Thomson announced he would seek additional public comment on the privacy regulation issued by HHS in December 2000).

[27] *Id.*

"privacy" must be viewed within a specific context. In the health care arena, that context is a long-standing belief between patient and doctor that medical information *should* be kept "confidential," juxtaposed with the *reality* of a complex health care treatment, payment, research, quality and marketing system that uses a significant amount of individually identifiable health care information without patients' explicit knowledge (albeit presumed by some patients with some dimly sensed fear). The role of government, I believe, is to bring clarity and confidence to this area. The goal of any system of privacy regulation must be to *enhance* the treatment, payment, research, and quality aspects of our health care system through creating a workable privacy system that provides patients with trust in their health care system, and at the same time, ensures that health care entities can engage in the marketing necessary to their financial health in a manner consistent with consumer consent.

Obviously, this is not necessarily an easy project. For example, while I doubt many observers of the current health care privacy debate would quibble with the first part of my previous sentence, I expect there would still be debate regarding what is a "workable system" of privacy regulation, what requirements "enhance" research or simply make life more "convenient" for researchers, and whether one uniform federal standard, with no state variations, is an essential component of such a system. Moreover, I am sure there would be disagreement regarding the extent of marketing that should be permitted without consumer consent. Nevertheless, I believe there is a shared conceptual principle that it is legitimate for government to intervene in this area so as to enhance patient trust in the health care system. The fact that this may be a hard job for government to do has never been a reason not to tackle it.

Let me conclude with some comments on an area that represents one of those "hard jobs" that need to be tackled—and that brings together some of my observations on employment discrimination and medical privacy. We are blessed to be living in a century where amazing medical and scientific advances are made every year.[28] The success of the Human Genome Project is one example of such an astonishing scientific breakthrough. But the researchers in that project, and in comparable private sector projects, correctly warn us that "genetic testing" and "genetic markers" must be treated with caution. The existence of a "genetic marker" does not necessarily mean an individual will develop a particular disease.[29] Moreover, employers and insurance companies may begin to view genetic information as useful information to compile, and then act upon such information for purposes that the general public, and Congress, may well find objectionable.[30] The principles that I articulated above should, I believe, lead Congress to clearly prohibit unjustified discrimination based on genetic markers for health conditions (as well as for the health conditions themselves), and to ensure that any medical privacy regulation clearly encompasses protection for genetic information.

Thank you for your attention. I look forward to responding to your questions.

Mr. STEARNS. Thank you.

Let me start with my questions. Professor Volokh, this is perhaps a more legal question, but I think our committee should tackle this and get the nuances here. What legal considerations would creating a property right in personal information trigger?

Mr. VOLOKH. Sure; this is one of the arguments that is sometimes made in support of information privacy speech restrictions, that they just create a property right in personal information. The Supreme Court has said that certain kinds of speech restrictions—specifically, copyright law is the best example—are justifiable on

[28] Of course, the existence of such breakthroughs only makes the reality of "medical mysteries" that much more heartbreaking. *See, e.g.*, Jerome Groopman, SECOND OPINION: STORIES OF INTUITION AND CHOICE IN THE CHANGING WORLD OF MEDICINE (2000); Jeff Wheelwright, THE IRRITABLE HEART: THE MEDICAL MYSTERY OF THE GULF WAR (2001); Hillary Johnsen, OSLER'S WEB: INSIDE THE LABYRINTH OF THE CHRONIC FATIGUE SYNDROME EPIDEMIC (1996). Nevertheless, medical advances continue to help a large number of individuals.

[29] For background information on the Human Genome Project and genetic research generally, see the website of the National Human Genome Research Institute at the National Institutes of Health, available at http://www.nhgri.nih.gov.

[30] Certain evidence seems to indicate that such activities are already taking place. See, e.g., U.S. Equal Employment Opportunity Commission, "EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans with Disabilities Act," available at http://www.eeoc.gov/press/2-9-01-c.html.